

University of Groningen

## Quality of life in partners of people with congestive heart failure

Luttik, Marie Louise; Jaarsma, Tiny; Lesman-Leegte, Ivonne; Sanderman, Robbert; Hagedoorn, Mariet

*Published in:*  
Journal of Advanced Nursing

*DOI:*  
[10.1111/j.1365-2648.2009.05004.x](https://doi.org/10.1111/j.1365-2648.2009.05004.x)

**IMPORTANT NOTE:** You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

*Document Version*  
Publisher's PDF, also known as Version of record

*Publication date:*  
2009

[Link to publication in University of Groningen/UMCG research database](#)

### *Citation for published version (APA):*

Luttik, M. L., Jaarsma, T., Lesman-Leegte, I., Sanderman, R., & Hagedoorn, M. (2009). Quality of life in partners of people with congestive heart failure: gender and involvement in care. *Journal of Advanced Nursing*, 65(7), 1442-1451. <https://doi.org/10.1111/j.1365-2648.2009.05004.x>

### **Copyright**

Other than for strictly personal use, it is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license (like Creative Commons).

The publication may also be distributed here under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license. More information can be found on the University of Groningen website: <https://www.rug.nl/library/open-access/self-archiving-pure/taverne-amendment>.

### **Take-down policy**

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

*Downloaded from the University of Groningen/UMCG research database (Pure): <http://www.rug.nl/research/portal>. For technical reasons the number of authors shown on this cover page is limited to 10 maximum.*

## ORIGINAL RESEARCH

## Quality of life in partners of people with congestive heart failure: gender and involvement in care

Marie Louise Luttik, Tiny Jaarsma, Ivonne Lesman, Robbert Sanderman &amp; Mariët Hagedoorn

Accepted for publication 12 February 2009

Correspondence to M.L. Luttik:  
e-mail: m.l.a.luttik@thorax.umcg.nl

Marie Louise Luttik PhD RN  
Senior Researcher  
Department of Cardiology, University  
Medical Centre Groningen, University of  
Groningen, The Netherlands

Tiny Jaarsma PhD RN  
Associate Professor  
Department of Cardiology, University  
Medical Centre Groningen, University of  
Groningen, The Netherlands

Ivonne Lesman PhD RN  
Senior Researcher  
Department of Cardiology, University  
Medical Centre Groningen, University of  
Groningen, The Netherlands

Robbert Sanderman PhD  
Professor  
Department of Health Psychology, University  
Medical Centre Groningen, The Netherlands

Mariët Hagedoorn PhD  
Professor  
Department of Health Psychology, University  
Medical Centre Groningen, The Netherlands

LUTTIK M.L., JAARSMA T., LESMAN I., SANDERMAN R. & HAGEDOORN M.  
(2009) Quality of life in partners of people with congestive heart failure: gender  
and involvement in care. *Journal of Advanced Nursing* 65(7), 1442–1451  
doi: 10.1111/j.1365-2648.2009.05004.x

**Abstract**

**Title.** Quality of life in partners of people with congestive heart failure: gender and involvement in care.

**Aim.** This paper is a report of a study conducted to investigate quality of life in partners of people with congestive heart failure in comparison to individuals living with a healthy partner.

**Background.** Congestive heart failure is a chronic debilitating disease with severe symptoms and complex treatment. The support of partners is essential in the management of congestive heart failure. Living with a chronic illness generally affects the quality of life of patients and their partners.

**Method.** Data were collected using a cross-sectional, comparative design between October 2002 and February 2005 with 303 partners of people with congestive heart failure. Reference data were collected in 304 age- and gender-matched individuals living with a healthy partner, drawn from the general population. All respondents completed questionnaires at home on quality of life and general well-being. Analysis of variance was used to analyse the data.

**Findings.** Overall, differences in quality of life between partners of people with heart failure and matched controls were small. However, substantial variation in the quality of life of partners was found by exploring the role of gender and involvement in care. Quality of life scores varied strongly for male and female partners who had to perform caregiving tasks. The performance of these caregiving tasks was negatively associated with the quality of life of female partners but not with that of male partners.

**Conclusion.** Female partners especially should not be overlooked when they become involved in personal care tasks. Nurses should not be reluctant to involve male partners in caring for women with heart failure.

**Keywords:** congestive heart failure, gender, nursing, partners, quality of life

## Introduction

Due to the ageing population and the enormous improvement in treatment options for cardiac diseases, congestive heart failure (CHF) in western societies has become epidemic (Cowie *et al.* 1997, McMurray & Stewart 2000). CHF is now recognized as a chronic disease and can be considered as the end-stage for many forms of heart disease and as the most common cause of death for hospitalized patients (O'Connell & Bristow 1994). It is a chronic debilitating condition with severe symptoms such as breathlessness, retention of sodium resulting in oedema, and fatigue. Treatment of CHF is complex and contains stringent lifestyle modifications and multi-drug regimens. Adherence to the treatment regimen is essential for clinical outcomes such as survival and quality of life (QOL) and therefore places strong demands on patients (VanderWal *et al.* 2005). Research indicates that those who have a network of supportive social relationships are doing better in terms of self-care (Sayers *et al.* 2008), QOL and mortality (House *et al.* 1988, Berkman *et al.* 1992, Case *et al.* 1992, Chin & Goldman 1997) compared to patients who are socially isolated. Partners are said to provide the most extensive and comprehensive support compared to other informal caregivers (Nijboer *et al.* 1998).

## Background

Although it seems obvious that CHF also places high demands on partners and therefore will also affect their lives, it is only recently that the consequences of living with a patient with CHF have been studied. Some studies indicate substantial psychological distress in partners (Karmilovich 1994, Rohrbaugh *et al.* 2002, Luttik *et al.* 2005, 2007a). Furthermore, some studies (Evangelista *et al.* 2002, Martensson *et al.* 2003, Pihl *et al.* 2005) compare the outcome in partners with the outcome in people with CHF themselves. These indicate that partners of people with CHF do better in physical health compared to people with CHF, but differences in mental health are less clear. Evangelista *et al.* (2002) found statistically significantly higher levels of emotional well-being in partners compared to patients, whereas other researchers (Martensson *et al.* 2003, Pihl *et al.* 2005) have found comparable scores. There have been two studies (Dracup *et al.* 2004, Luttik *et al.* 2005) in which the investigators compared their scores to age-adjusted norm scores drawn from the general population. Both showed that emotional well-being in partners of people with CHF was statistically

significantly lower. However, these partners have never been compared to well-matched individuals from the general population living with a healthy partner, meaning that the real impact of CHF on partners is still unknown.

Another limitation of these earlier studies examining the impact of CHF on partners is the failure to take into account the gender of the partner. All studies discussed above had over-representation of male patients and female partners in their samples. Review of the literature identifies that gender is a key factor associated with psychological distress in partners of people who are chronically ill. In general, female partners of chronically ill patients report more distress when compared to male partners (Miller & Cafasso 1992, Lutzky & Knight 1994, Hagedoorn *et al.* 2000, 2008, Rohrbaugh *et al.* 2002, Pinquart & Sörensen 2006). Several theories to explain this phenomenon have been discussed in the literature, mostly relying on differences in individual characteristics, such as the use of different coping strategies or perceived competence in providing support (Barusch & Spaid 1989, Mirowsky & Ross 1995, Hagedoorn *et al.* 2003).

Partners are said to provide the most extensive and comprehensive care and are less likely to receive assistance (Nijboer *et al.* 1998). The impact of providing care to a chronically ill family member has been studied extensively and appears to be associated with both negative and positive effects on caregivers' lives (Kriegsman *et al.* 1994, Pinquart & Sörensen 2003, 2006). Some studies reveal positive experiences from providing care in terms of love, rewards, and challenges that may increase feelings of satisfaction, pride and self-esteem (Kramer 1997). However, most have focussed on negative effects of caregiving. Several studies across varying chronic illnesses have documented statistically significantly higher levels of psychological distress in caregiving spouses compared to non-spousal caregivers (Kriegsman *et al.* 1994, Pinquart & Sörensen 2003, 2007), and some even indicate an impact on physical health and mortality in caregivers (Schulz & Beach 1999, Vitaliano *et al.* 2003, Pinquart & Sörensen 2007).

As one of the shortcomings in caregiving research that may explain low levels of distress in partners, Pinquart and Sörensen (2003) mention the lack of studies that describe the actual involvement of caregivers in providing care. Schulz *et al.* (1997) have suggested that researchers may underestimate caregiver stress because they often define caregivers as individuals who share the household with an impaired family member, without assessing

whether this individual actually provides care. Most studies of QOL in partners of people with CHF have not taken into account the amount of actual care given. One exception is a study by Karmilovich (1994) that showed a statistically significant association between the performance of caregiving tasks and stress in partners of people with CHF. Similarly, we recently reported that the performance of caregiving tasks, especially personal care tasks (e.g. assisting with washing, eating and mobility in and around the house), was statistically significantly associated with higher levels of caregiver burden in partners of people with CHF (Luttik *et al.* 2007b). These studies also indicate that there is substantial variance in the amount of care provided.

## The study

### Aim

The aim of the study was to investigate QOL in partners of people with CHF in comparison to individuals living with a healthy partner.

On the basis of earlier studies with other chronic illnesses, we hypothesized that partners of people with CHF would report lower QOL than individuals with a healthy partner. Furthermore, we expected this difference to be most pronounced in female partners. However, overall differences may be smaller than often assumed. In the second phase of this study, we investigated the role of actual involvement in care, as this is a neglected variable within research examining QOL in partners of people with CHF. We hypothesized that involvement in care would be negatively associated with QOL. Furthermore, a possible interaction between involvement in care and gender was explored.

### Design

We used a cross-sectional, comparative design. A population of partners of people with CHF was compared to an age- and gender-matched control group drawn from the general population.

### Participants

#### *Partners of people with CHF*

Partners of people with CHF were recruited from the Dutch NHF-COACH trial, which is a randomized clinical trial conducted in 17 centers in the Netherlands studying

the effects of education and counselling in patients with CHF (Jaarsma *et al.* 2004, Jaarsma *et al.* 2008). Patients were included between October 2002 and February 2005 when hospitalized for symptomatic HF (NYHA II–IV). Those included were at least 18 years of age, with evidence of structural underlying heart disease. Major exclusion criteria were: any invasive procedure or cardiac surgery intervention within the last 6 months or planned during the following 3 months, ongoing evaluation for heart transplantation, inability to complete the questionnaires, or inability or unwillingness to give informed consent. There were no specific inclusion or exclusion criteria for partners, except that they had to be able and willing to complete a questionnaire.

#### *Individuals living with a healthy partner*

To compare QOL of partners of people with CHF with a reference group of individuals living with a healthy partner, data from a national survey were used.

### Data collection

#### *Procedures*

Clinical data and demographics for all people with CHF were collected by chart review and patient interview during the initial hospital admission. One year after patient discharge, partners received a self-report questionnaire at home, which they were asked to complete independently of the patient. Independent interviewers collected the questionnaires when visiting partners at home.

In the survey, nine local district council offices in different areas in the Netherlands were asked for a random sample of addresses of 500 or 1000 participants who were at least 55 years old and who were not living at the same address. Between July and August 2005, 5500 questionnaires were distributed, accompanied by a letter in which participants were invited to complete the questionnaires and return them in a prestamped envelope. Confidentiality was guaranteed.

#### *Quality of life*

Quality of life was assessed by two measures: the Medical Outcome Study 36-item General Health Survey (RAND-36) and Cantril's Ladder. The RAND-36 is a widely used self-report questionnaire measuring general health and is considered to be well-validated (RAND Health Sciences Program 1992, VanderZee *et al.* 1996a, 1996b). The questionnaire contains 36 items reflecting nine dimensions: physical functioning, role limitations due to physical functioning, bodily pain, general health perception,

vitality, social functioning, role limitations due to emotional functioning, mental health and perceived health change. For each domain, scores range from 0 to 100, with a higher score indicating better health. Reliability of the nine domains was satisfactory, with Cronbach's alpha's ranging from 0.71 for the domain of social functioning to 0.92 for the domain of physical functioning (VanderZee *et al.* 1996a, 1996b).

We also used Cantril's Ladder of life (Cantril 1965) as a measure of 'global well-being'. The concept of well-being is related to important aspects of QOL such as psychosocial adjustment and functional capabilities (Jaarsma *et al.* 1999), and has been used in various cardiovascular studies (Senten 1991, Jaarsma & Kastermans 1997). Respondents were asked to rate their sense of well-being on a ladder, with 10 reflecting the best possible life imaginable and 0 reflecting the worst possible life imaginable. A higher score indicates better well-being.

#### *Actual involvement in care*

Actual involvement in care was assessed using the Dutch Objective Burden Inventory (DOBI) (Luttik *et al.* 2008). This contains four different domains of caregiving tasks. For the purposes of this study, the domain of tasks regarding personal care such as support in eating, dressing and bathing (11 items in total) was assessed. A sum score can be computed as the average of the subsequent items with a range between 1.0 (providing no care) to 3.0 (providing a great deal of care). Findings in the original study (Luttik *et al.* 2008) supported the reliability (Cronbach's alpha 0.83 for the subscale personal care) and validity of the scale. In the current study, we dichotomized this variable into two categories: providing no care (0) and providing care (1).

#### **Ethical considerations**

The appropriate ethics committee approved the COACH study and the investigation conforms to the principles outlined in the Declaration of Helsinki. A cardiologist and a research nurse approached all patients to provide oral and written information. Written informed consent was obtained after a minimum of 24 hours. Twelve months after the initial inclusion of the patient, partners were approached by mail with a letter and a questionnaire. Return of a completed questionnaire was taken as consent to participate.

The reference group of individuals living with a healthy partner was approached by the distribution of questionnaires

accompanied by a letter in which they were informed of the study and invited to participate. Anonymity of data was guaranteed.

#### **Data analyses**

All data were entered into an SPSS (14.5) database (SPSS Inc., Chicago, IL, USA) and descriptive statistics were used to describe the study participants. To have a fair test of differences in QOL between partners of people with CHF and controls from the general population living with a healthy partner, partners were matched by gender and age. The General Linear Model module of SPSS (two-way ANOVA) was used to build models with the QOL measures as the dependent variables. Gender (male vs. female) and group (partners of people with CHF vs. individuals living with a healthy partner) were entered as factors in each model, along with the interaction term gender by group.

Within partners of people with CHF, we further analysed the role of the actual involvement in care. The two-way ANOVA technique was used to build models with the QOL measures as the dependent variables. Involvement in personal care (yes vs. no), gender (male vs. female), and the interaction between involvement in care and gender were entered into the models as the independent variables.

Simple effects analyses and multiple comparison procedures (LSD) were carried out only to interpret statistically significant interactions.

#### **Results**

##### **Response and sample characteristics**

The COACH trial study sample consisted of 1023 people with CHF. Within this sample, 605 (59%) were married or living with a partner. At 12 months, 441 questionnaires were sent out (112 patients had died before 12 months, 29 left the study before 12 months and 23 left for logistical reasons); of these 407 (92%) partners responded and returned their questionnaires. Reasons for non-response include logistical reasons (10), health problems of partners (14), not willing to participate (10). In six cases, questionnaires were incomplete and could not be used.

From the 5500 questionnaires distributed among community-dwelling elders, 2497 (45%) were returned. Of these, 1712 respondents were married or living with a partner and 1288 indicated that they were living with a healthy partner.

The population of partners of people with CHF ( $n = 401$ ) was predominantly female, with age ranging

from 25 to 89 years and a mean age of 67 ( $\pm 12$ ) years. The reference group of individuals living with a healthy partner ( $n = 1288$ ) were all above 55 years old, with a mean age of 66 ( $\pm 7$ ), and was predominantly male (65%). After matching for age and gender, the study sample consisted of 303 partners of people with CHF and 304 individuals of healthy partners, both with a mean age of 69 years. In previous publications (Luttik *et al.* 2007b, 2008), we used subsamples of the current study sample to describe caregiver burden and to develop an inventory of CHF specific caregiving tasks.

### Comparison of partners of people with CHF and with healthy individuals

Two-way analysis of variance revealed the expected interaction effect between group (partners of people with CHF vs. individuals living with a healthy partner) and gender for general well-being,  $F(1,581) = 4.526$ ,  $P < 0.05$ , and for perceived health change,  $F(1,604) = 4.283$ ,  $P < 0.05$ . Simple effects analyses indicated that female partners of people with CHF performed worse than female partners of a

healthy person on both outcomes [ $F(1,578) = 10.43$ ,  $P = 0.001$  and  $F(1,601) = 12.10$ ,  $P = 0.001$  for general well-being and perceived health change respectively], whereas male partners of people with CHF did not show statistically significantly different scores when compared to male partners of healthy persons [ $F(1,578) = 0.64$ ,  $P = 0.57$  and  $F(1,601) = 0.10$ ,  $P = 0.75$  respectively]. Furthermore, a main effect of group was found for the domain of general health perception,  $F(1,598) = 4.066$ ,  $P < 0.05$ , with partners of people with CHF reporting lower general health than partners of healthy persons, regardless of their gender. In addition, main effects of gender were found for the domains of bodily pain,  $F(1,605) = 6.31$ ,  $P < 0.05$ , vitality;  $F(1,600) = 6.133$ ,  $P < 0.05$ , and mental health,  $F(1,600) = 6.083$ ,  $P < 0.05$ . For all three domains, female respondents had lower scores compared to male respondents, indicating more pain, lower vitality and lower mental health in women, regardless of whether the partner had CHF or not. The results revealed no statistically significant effects for the domains of physical functioning, role limitations because of physical problems, role limitation because of emotional problems and social functioning. Table 1 shows all  $F$ -values and the mean levels of QOL of

**Table 1** Quality of life in partners of people with congestive heart failure vs. elders with a healthy partner

	Male respondents		Female respondents		Test statistic		
	Individuals living with healthy partner ( $n = 81$ )	Partners of people with CHF ( $n = 81$ )	Partners of people with CHF ( $n = 222$ )	Individuals living with healthy partner ( $n = 223$ )	Group effect $F$ value ( $P$ value)	Gender effect $F$ value ( $P$ value)	Interaction effect $F$ value ( $P$ value)
Well-being RAND-36	7.47 (1.0) <sup>b</sup>	7.58 (1.5) <sup>b</sup>	7.04 (1.7) <sup>a</sup>	7.40 (1.1) <sup>b</sup>	1.47 (0.22)	4.102 (0.04)	4.53 (0.03)
Physical functioning	68.9 (27.1)	67.9 (28.1)	69.1 (26.6)	68.8 (26.4)	0.02 (0.89)	0.05 (0.82)	0.07 (0.78)
Role limitations physical	68.5 (39.1)	67.6 (40.0)	63.9 (41.4)	67.8 (40.1)	0.41 (0.52)	0.35 (0.55)	0.14 (0.71)
Bodily pain	80.7 (23.5)	78.9 (23.7)	72.8 (25.9)	75.5 (23.6)	1.02 (0.31)	6.31 (0.01)	0.05 (0.82)
General health perceptions	61.1 (18.8)	57.1 (22.6)	59.8 (20.4)	63.3 (19.6)	4.07 (0.04)	1.68 (0.19)	0.02 (0.89)
Vitality	68.4 (20.3)	67.6 (19.9)	63.2 (20.4)	63.7 (19.0)	0.13 (0.72)	6.13 (0.01)	0.11 (0.92)
Social functioning	79.7 (25.1)	81.6 (21.8)	79.9 (23.5)	80.1 (24.5)	0.14 (0.71)	0.10 (0.75)	0.22 (0.64)
Role limitations emotional	84.4 (31.1)	82.7 (34.2)	80.1 (34.0)	81.2 (34.5)	0.02 (0.65)	0.85 (0.36)	0.01 (0.94)
Mental health	78.8 (16.7) <sup>a</sup>	77.4 (16.5)	73.3 (19.1)	75.1 (15.3)	1.08 (0.29)	6.08 (0.01)	0.18 (0.89)
Perceived health change	44.7 (18.4) <sup>a</sup>	45.7 (18.9) <sup>ab</sup>	43.6 (17.7) <sup>a</sup>	49.8 (19.8) <sup>b</sup>	2.34 (0.13)	0.72 (0.40)	4.28 (0.04)

Additional multiple comparison tests (LSD) were used to facilitate the interpretation of interaction effects. In each row, means that do not share a common superscript are statistically significantly different ( $P < 0.05$ ).

Mean<sup>b</sup> differs from mean<sup>a</sup>.

Mean<sup>b</sup> does not differ from mean<sup>ab</sup> or mean<sup>b</sup>.

Mean<sup>a</sup> differs from mean<sup>b</sup>.

Mean<sup>a</sup> does not differ from mean<sup>ab</sup> or mean<sup>a</sup>.

'Group effect' refers to the effect of living with a person with *congestive heart failure* vs. living with a healthy individual.



**Table 2** Quality of life in male and female partners of people with congestive heart failure stratified for the performance of caregiving tasks

	Male respondents		Female respondents		Test statistics		
	Tasks performed ( <i>n</i> = 52)	No task performed ( <i>n</i> = 29)	Tasks performed ( <i>n</i> = 101)	No tasks performed ( <i>n</i> = 118)	Task effect <i>F</i> value ( <i>P</i> value)	Gender effect <i>F</i> value ( <i>P</i> value)	Interaction effect <i>F</i> value ( <i>P</i> value)
Well-being	7.51 (1.2)	7.72 (2.0)	6.76 (1.6)	7.28 (1.7)	2.78 (0.10)	7.22 (0.01)	0.49 (0.48)
RAND-36							
Physical functioning	69.7 (26.0)	64.7 (31.9)	65.1 (28.6)	72.5 (24.5)	0.10 (0.75)	0.19 (0.66)	2.96 (0.09)
Role limitations physical	72.1 (32.3)	59.5 (45.5)	58.9 (41.5)	68.2 (41.4)	0.09 (0.76)	0.16 (0.68)	3.97 (0.05)
Bodily pain	91.9 (23.1) <sup>b</sup>	73.5 (24.4) <sup>ab</sup>	68.6 (27.2) <sup>a</sup>	76.6 (24.4) <sup>b</sup>	0.00 (0.95)	2.31 (0.13)	5.87 (0.02)
General health perceptions	58.5 (20.6)	54.7 (26.1)	57.7 (21.6)	61.5 (19.4)	0.00 (0.99)	1.12 (0.29)	1.77 (0.18)
Vitality	69.5 (18.4) <sup>b</sup>	64.1 (22.3) <sup>ab</sup>	58.9 (21.2) <sup>a</sup>	67.3 (19.1) <sup>b</sup>	0.30 (0.58)	1.92 (0.17)	6.67 (0.01)
Social functioning	82.5 (20.4) <sup>b</sup>	80.2 (24.4) <sup>ab</sup>	72.8 (26.8) <sup>a</sup>	85.9 (18.7) <sup>b</sup>	3.21 (0.07)	0.42 (0.52)	6.47 (0.01)
Role limitations emotional	85.2 (32.6) <sup>ab</sup>	78.2 (37.0) <sup>ab</sup>	74.0 (36.8) <sup>a</sup>	85.3 (30.7) <sup>b</sup>	0.21 (0.64)	0.21 (0.65)	4.10 (0.04)
Mental health	78.0 (14.7) <sup>b</sup>	76.3 (19.6) <sup>b</sup>	68.5 (21.7) <sup>a</sup>	77.8 (15.4) <sup>b</sup>	2.42 (0.12)	2.71 (0.10)	5.10 (0.02)
Perceived health change	48.1 (19.1)	41.4 (18.0)	42.3 (19.6)	45.1 (15.4)	0.66 (0.42)	0.17 (0.68)	3.94 (0.05)

Additional multiple comparison tests (LSD) were used to facilitate the interpretation of interaction effects. In each row, means that do not share a common superscript are statistically significantly different ( $P < 0.05$ ).

Mean<sup>b</sup> differs from mean<sup>a</sup>.

Mean<sup>b</sup> does not differ from mean<sup>ab</sup> or mean<sup>b</sup>.

Mean<sup>a</sup> differs from mean<sup>b</sup>.

Mean<sup>a</sup> does not differ from mean<sup>ab</sup> or mean<sup>a</sup>.

'Task effect' refers to the effect of performing personal care tasks vs. no personal care tasks performed.

partners of people with CHF and their age-matched controls, stratified by gender. For the dimensions of the RAND 36, a 5-point difference is assumed as a clinically relevant difference; taking this into account, differences are small.

### Partners of people with CHF and QOL: impact of gender and actual involvement in care

Within the population of partners of people with CHF, we further explored the impact of the actual involvement in care, in terms of performing personal care tasks, and the possible interaction between care and gender.

For general well-being we found a main effect of gender  $F(1,291) = 7.22$ ,  $P < 0.01$ , with female partners of people with CHF reporting lower scores compared to males (Table 2). Furthermore, we found statistically significant interactions between gender and involvement in care for the following QOL domains: social functioning  $F(1,299) = 6.47$ ,  $P < 0.05$ , role limitations because of physical problems  $F(1,299) = 3.97$ ,  $P < 0.05$ , role limitations because of emotional problems  $F(1,298) = 4.10$ ,  $P < 0.05$ , mental health  $F(1,297) = 5.07$ ,  $P < 0.05$ , vitality  $F(1,297) = 6.68$ ,  $P < 0.05$ , bodily pain  $F(1,299) = 5.87$ ,  $P < 0.05$ , and perceived health change  $F(1,299) = 3.94$ ,  $P < 0.05$ . Interestingly,

simple effects analyses for the domains of mental health, role limitations because of emotional problems, bodily pain, vitality and social functioning revealed that actual involvement in care was associated with QOL in female partners ( $F$  ranging from 5.18 to 18.24,  $P < 0.02$ ), but not with QOL in male partners ( $F$  ranging from 0.03 to 2.04,  $P > 0.15$ ). Simple effect analyses for the domains of role limitations physical and perceived health change did not reach statistical significance for women or for men. We performed the same analyses with correction for severity of CHF in patients by adding the New York Heart Association classification (I-IV) into the model as a covariate. Although NYHA class was independently related to some domains of QOL in partners of people with CHF, it did not affect the interaction effects that were found for gender and involvement in care. Because of missing values in NYHA class, we decided to present the results without NYHA class in the model.

## Discussion

### Study limitations

In this paper, we present unique data on the QOL of a relatively new group of caregivers, namely partners of people

with CHF. However, the results of the study need to be interpreted taking note of some limitations. First, the cross-sectional design of the study precludes us from drawing conclusions about causality. For example, we cannot draw any conclusions about whether the performance of caregiving tasks actually causes a low perceived QOL. Second, our conclusions are based on, and are therefore restricted to, a sample representing older partners of people with CHF, above 55 years old. However, we consider that our sample is representative of the CHF population in general because CHF is specifically prevalent in older people. Our sample of partners of people with CHF represented partners of people with CHF who had been diagnosed at least 12 months before. In our qualitative study on partners of people with CHF (Luttik *et al.* 2007a), partners mentioned distress especially directly after diagnosis or after hospital admission. Therefore, at that stage of the disease, QOL scores may be more impaired compared to our results. Further research at different stages of the disease is necessary. Last, as in most studies on caregiving, our sample had a relatively small representation of male partners of people with CHF, which may have given less power, especially to detect differences between male partners and the performance of caregiving tasks.

## Discussion of results

Our first goal was to investigate the QOL of partners of people with CHF and to explore the influence of the caregiving role and gender. Data on the QOL of 300 partners of people with CHF were compared to individuals with healthy partners drawn from the general population (adjusted for age differences). Results showed only small differences in quality between these two groups. These findings are in line with the results of Pinquart and Sörensen (2003), who also found small differences in subjective well-being (and physical health), especially between caregivers of physically (non-demented) ill and non-caregivers. Furthermore, Hagedoorn *et al.* (2008) also reported that levels of psychological distress in partners of cancer patients were only moderately higher compared to individuals drawn from the general population. Since our sample of partners of people with CHF can be considered as fairly large and representative for older partners of people with CHF (above 55 years old), we may conclude that these partners do not seem to be specific in that they suffer as much or as little as partners of people with other physical illnesses. We did not measure the cognitive functioning of people with CHF; however, from other studies it is known that a substantial proportion of people with CHF show a decline in cognitive

functioning (Trojano *et al.* 2003). As we know from the caregiving literature on people with Alzheimer disease that cognitive impairment is an important predictor for psychological distress in partners (Pinquart & Sörensen 2003), it would be relevant to investigate the impact of this variable in future research.

As hypothesized, gender appears to be an important contextual factor in QOL. In terms of general well-being and changes in perceived health, the interrelation with gender becomes clear through the statistically significant interaction between group and gender. Partner's illness was found to be associated with lower well-being and a negative change in perceived health in women but not in men. This is in line with earlier findings (Hagedoorn *et al.* 2000, 2001, Pinquart & Sörensen 2006). Furthermore, differences in the dimensions of mental health, pain and vitality were mainly related to gender, with female respondents performing worse, regardless of whether they were the partner of a person with CHF or a healthy individual (cf. Hagedoorn *et al.* 2008).

Although overall differences were small, we did find substantial variation in QOL of partners of people with CHF by exploring the impact of performing caregiving tasks and gender. A statistically significant interaction was found between actual involvement in care and gender for several domains of QOL. Scores varied strongly for male and female partners who had to perform caregiving tasks such as assisting with washing, dressing and mobility in and around the house. This interaction indicates that the performance of these tasks was associated with negative outcomes in female partners. Male partners, however, did not seem to suffer from taking care of women with CHF. These findings cannot be explained by gender differences in the number of caregiving tasks performed. In contrast to earlier findings (Pinquart & Sörensen 2006), male partners of people with CHF in our study performed more personal caregiving tasks compared to female partners of people with CHF. A more plausible explanation may lie in role identity theory: differences in role identities between men and women. Taking care of the family, partner and children is mainly seen as the responsibility of women, whereas men are considered to provide financial and other resources. As a result of these different role identities, stressors that have a strong effect on women may have a weaker effect on men and vice versa (Hagedoorn *et al.* 2003). Previous studies have shown that women are most distressed by stressors that involve social and family relationships, whereas men feel distressed mostly because of work and financial events (Conger *et al.* 1993). Following this hypothesis, providing personal care to a



### What is already known about this topic

- Congestive heart failure is a chronic debilitating disease with severe symptoms and a complex treatment regimen.
- The support of partners is essential in terms of self-care, quality of life, readmission rates and mortality.
- Living with a chronic illness generally affects the quality of life of patients and their partners.

### What this paper adds

- Overall, differences in quality of life between partners of people with congestive heart failure and individuals from the general population living with a healthy partner are small.
- Gender is a key concept to consider when studying quality of life of partners of people with congestive heart failure.
- The performance of caregiving tasks is statistically significantly associated with vitality, pain, mental and social aspects of quality of life in female partners, but not with quality of life in male partners.

### Implications for practice and/or policy

- The psychological well-being, especially of female partners of people with heart failure, should be assessed carefully.
- Female partners involved in the personal care of people with heart failure need special attention in terms of their psychological well-being.
- Nurses should not be reluctant to involve male partners in the care of women with heart failure.

patient with CHF may more stressful for women than for men.

### Conclusion

The psychological well-being, of especially female partners of people with heart failure, should be assessed carefully. Female partners involved in the personal care of people with heart failure need special attention in terms of their psychological well-being. Nurses should not be reluctant to involve male partners in the care of women with heart failure.

### Acknowledgements

We thank Prof. Dr A. Ranchor of the Department of Health Psychology, University of Groningen for her cooperation in the Dutch National survey on Physical and Psychological Health in the Elderly.

### Funding

The NHF-COACH was supported by the Netherlands Heart Foundation (Grant 2000/Z003).

### Conflict of interest

No conflict of interest has been declared by the authors.

### Author contributions

MLL, TJ & MH were responsible for the study conception and design. MLL & IL performed the data collection. MLL & MH performed the data analysis. MLL & MH were responsible for the drafting of the manuscript. MLL, TJ, IL, RS & MH made critical revisions to the paper for important intellectual content. MLL & MH provided statistical expertise. TJ obtained funding. MLL, TJ & MH supervised the study.

### References

- Barusch A.S. & Spaid W.M. (1989) Gender differences in caregiving: why do wives report greater burden? *Gerontologist* 29, 667–676.
- Berkman L.F., Leo-Summers L. & Horwitz R.I. (1992) Emotional support and survival after myocardial infarction. A prospective, population based study of the elderly. *Annals of Internal Medicine* 117, 1003–1009.
- Cantril H. (1965) *The Pattern of Human Concerns*. Rutgers University, New Brunswick.
- Case R.B., Moss A.J., Case N., McDermott M. & Eberly S. (1992) Living alone after myocardial infarction. Impact on prognosis. *Journal of the American Medical Association* 267, 515–519.
- Chin M.H. & Goldman L. (1997) Correlates of early hospital readmission or death in people with congestive heart failure. *American Journal of Cardiology* 79, 1640–1644.
- Conger R.D., Lorenz F.O., Elder G.H., Simons R.L. & Ge X. (1993) Husband and wife differences in response to undesirable life events. *Journal of Health and Social Behavior* 34, 71–88.
- Cowie M.R., Mosterd A., Wood D.A., Deckers J.W., Poole-Wilson P.A., Sutton G.C. & Grobbee D.E. (1997) The epidemiology of heart failure. *European Heart Journal* 18, 208–225.
- Dracup K., Evangelista L.S., Doering L., Tullman D., Moser D.K. & Hamilton M. (2004) Emotional well-being in spouses of people with advanced heart failure. *Heart and Lung* 33, 354–361.

- Evangelista L.S., Dracup K., Doering L., Westlake C., Fonarow G.C. & Hamilton M. (2002) Emotional well-being of heart failure patients and their caregivers. *Journal of Cardiac Failure* 8, 300–305.
- Hagedoorn M., Buunk B.P., Kuijer R.G., Wobbes T. & Sanderman R. (2000) Couples dealing with cancer: role and gender differences regarding psychological distress and quality of life. *Psycho-oncology* 9, 232–242.
- Hagedoorn M., Sanderman R., Ranchor A.V., Brilman E.I., Kempen G.I. & Ormel J. (2001) Chronic disease in elderly couples: are women more responsive to their spouses' health condition than men? *Journal of Psychosomatic Research* 51, 693–696.
- Hagedoorn M., Sanderman R., Buunk B.P. & Wobbes T. (2003) Failing in spousal caregiving: the 'identity-relevant stress' hypothesis to explain sex differences in caregiver distress. *British Journal of Health Psychology* 7, 481–494.
- Hagedoorn M., Sanderman R., Bolks H.N., Tuinstra J. & Coyne J.C. (2008) Distress in couples coping with cancer: a meta-analysis and critical review of role and gender effects. *Psychological Bulletin* 134, 1–30.
- House J.S., Landis K.R. & Umberson D. (1988) Social relationships and health. *Science* 241, 540–545.
- Jaarsma T. & Kasternans M.C. (1997) Recovery and quality of life one year after coronary artery bypass grafting. *Scandinavian Journal of Caring Sciences* 11, 67–72.
- Jaarsma T., Halfens R., Abu-Saad H.H., Dracup K., Stappers J. & van Ree J. (1999) Quality of life in older people with systolic and diastolic heart failure. *European Journal of Heart Failure* 1, 151–160.
- Jaarsma T., van der Wal M.H.L., Hogenhuis J., Lesman I., Luttik M.L., Veeger N.J. & van Veldhuisen D.J. (2004) Design and methodology of the COACH study: a multicenter randomised Coordinating study evaluating Outcomes of Advising and Counselling in Heart failure. *European Journal of Heart Failure* 6, 227–233.
- Jaarsma T., van der Wal M.H.L., Lesman-Leegte I., Luttik M.L., Hogenhuis J., Veeger N.J., Sanderman R., Hoes A.W., van Gilst W.H., Lok D.J., Dunselman P.H., Tijssen J.G., Hillige H.L. & Veldhuisen D.J. (2008) Effect of moderate or intensive disease management program on outcome in patients with heart failure; Coordinating Study Evaluating Outcomes of Advising and Counseling in Heart Failure (COACH). *Archives of Internal Medicine* 168, 316–324.
- Karmilovich S.E. (1994) Burden and stress associated with spousal caregiving for individuals with heart failure. *Progress in Cardiovascular Nursing* 9, 33–38.
- Kramer B.J. (1997) Gain in the caregiving experience; where are we? *Gerontologist* 37, 218–232.
- Kriegsman D.M.W., Penninx B.W.J.H. & van Eijk J.Th.M. (1994) Chronic disease in the elderly and its impact on the family: a review of the literature. *Family Systems Medicine* 12, 249–267.
- Luttik M.L., Jaarsma T., Veeger N.J. & van Veldhuisen D.J. (2005) For better and for worse: quality of life impaired in HF patients as well as in their partners. *European Journal of Cardiovascular Nursing* 4, 11–14.
- Luttik M.L., Blaauwbroek A., Dijkster A. & Jaarsma T. (2007a) Living with heart failure: partner perspectives. *Journal of Cardiovascular Nursing* 22, 131–137.
- Luttik M.L., Jaarsma T., Veeger N., Tijssen J., Sanderman R. & van Veldhuisen D.J. (2007b) Caregiver burden in partners of heart failure patients; limited influence of disease severity. *European Journal of Heart Failure* 9, 695–701.
- Luttik M.L., Jaarsma T., Tijssen J., van Veldhuisen D.J. & Sanderman R. (2008) The objective burden in partners of heart failure patients; development and validation of the Dutch Objective Burden Inventory (DOBI). *European Journal of Cardiovascular Nursing* 7, 3–9.
- Lutzky S.M. & Knight B.G. (1994) Explaining gender differences in caregiver distress: the roles of emotional attentiveness and coping styles. *Psychology and Aging* 9, 513–519.
- Martensson J., Dracup K., Canary C. & Fridlund B. (2003) Living with heart failure: depression and quality of life in patients and spouses. *Journal of Heart and Lung Transplantation* 22, 460–467.
- McMurray J.J.V. & Stewart S. (2000) Epidemiology, aetiology, and prognosis of heart failure. *Heart* 83, 596–602.
- Miller B. & Cafasso L. (1992) Gender differences in caregiving: fact or artefact? *Gerontologist* 32, 498–507.
- Mirowsky J. & Ross C.E. (1995) Sex differences in distress – real or artefact. *American Sociological Review* 60, 449–468.
- Nijboer C., Tempelaar R., Sanderman R., Triemstra M., Spruijt R.J. & van den Bos C. (1998) Cancer and caregiving: the impact on the caregiver's health. *Psycho-oncology* 7, 3–13.
- O'Connell J.B. & Bristow M.R. (1994) Economic impact of heart failure in the United States: time for a different approach. *Journal of Heart and Lung Transplantation* 13, S107–S112.
- Pihl E., Jacobsson A., Fridlund B., Stromberg A. & Martensson J. (2005) Depression and health-related quality of life in elderly patients suffering from heart failure and their spouses: a comparative study. *European Journal of Heart Failure* 7, 583–589.
- Pinquart M. & Sörensen S. (2003) Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychology and Aging* 18, 250–267.
- Pinquart M. & Sörensen S. (2006) Gender differences in caregiver stressors, social resources, and health; an updated meta-analysis. *Journal of Gerontology; Psychological Sciences and Social Sciences* 61, 33–45.
- Pinquart M. & Sörensen S. (2007) Correlates of physical health of informal caregivers: a meta-analysis. *Journal of Gerontology; Psychological Sciences and Social Sciences*, 62B, 126–137.
- RAND Health Sciences Program (1992) *RAND 36-item Health Survey 1.0*. RAND, Santa Monica, CA.
- Rohrbaugh M.J., Cranford J.A., Shoham V., Nicklas J.M., Sonnega J.S. & Coyne J.C. (2002) Couples coping with congestive heart failure: role and gender differences in psychological distress. *Journal of Family Psychology* 16, 3–13.
- Sayers S.L., Riegel B., Pawlowksi S., Coyne J.C. & Samaha F.F. (2008) Social support and self-care of people with heart failure. *Annals of Behavioral Medicine* 35, 70–79.
- Schulz R. & Beach S.R. (1999) Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *Journal of the American Medical Association* 282, 2215–2219.
- Schulz R., Newsom J., Mittelman M., Burton L., Hirsch C. & Jackson S. (1997) Health effects of caregiving: the caregiver health effects study: an ancillary study of the Cardiovascular Health Study. *Annals of Behavioral Medicine* 19, 110–116.

- Senten C.M.S. (1991) *The Well-being of Patients Having CAB Surgery: A Test of Orem's Self-care Nursing Theory*. University of Maastricht, Maastricht, The Netherlands.
- Trojano L., Antonelli Incalzi R., Acanfora D., Picone C., Mecocci P. & Rengo F. (2003) Cognitive impairment; a key feature of congestive heart failure in the elderly. *Journal of Neurology* **250**, 1456–1463.
- VanderWal M.H.L., Jaarsma T. & van Veldhuisen D.J. (2005) Non-compliance in people with heart failure; how can we manage it? *European Journal of Heart Failure* **7**, 5–17.
- VanderZee K.I., Sanderman R. & Heyink J. (1996a) A comparison of two multidimensional measures of health status; the Nottingham Health Profile and the RAND 36-item Health Survey 1.0. *Quality of Life Research* **5**, 165–174.
- Van der Zee K.I., Sanderman R., Heyink J.W. & de Haes H. (1996b) Psychometric qualities of the RAND 36-item health survey 1.0: a multidimensional measure of general health status. *International Journal of Behavioral Medicine* **3**, 104–122.
- Vitaliano P.P., Zhang J. & Scanlan J.M. (2003) Is caregiving hazardous to one's physical health? A meta-analysis *Psychological Bulletin* **129**, 946–972.

The *Journal of Advanced Nursing (JAN)* is an international, peer-reviewed, scientific journal. *JAN* contributes to the advancement of evidence-based nursing, midwifery and health care by disseminating high quality research and scholarship of contemporary relevance and with potential to advance knowledge for practice, education, management or policy. *JAN* publishes research reviews, original research reports and methodological and theoretical papers.

For further information, please visit the journal web-site: <http://www.journalofadvancednursing.com>